Citation: Frood, S., van Rooyen, D. R. M. & Ricks, E. (2018). Health and social care professionals' anguish in providing care and support to children who are AIDS orphans in Nelson Mandela Bay: A qualitative study. International Journal of Africa Nursing Sciences, 9, pp. 31-37. doi: 10.1016/j.ijans.2018.07.002

International Journal of Africa Nursing Sciences 9 (2018) 31–37

Contents lists available at ScienceDirect

International Journal of Africa Nursing Sciences

journal homepage: www.elsevier.com/locate/ijans

Health and social care professionals' anguish in providing care and support to children who are AIDS orphans in Nelson Mandela Bay: A qualitative study

Sharron Frood[a], Dalena (R.M.) van Rooyen[b,*], Esmeralda Ricks[c]

[a] Department of Child Health and Family Health, Kings College London, United Kingdom
[b] Faculty of Health Sciences, Nelson Mandela University, Port Elizabeth, South Africa
[c] Department of Nursing Sciences, Nelson Mandela University, Port Elizabeth, South Africa

ARTICLE INFO

Keywords:
AIDS orphans
Primary health care nurses
Psychologists
Social workers
South Africa
Care
Support
Township communities

ABSTRACT

Background: Orphanhood is a major consequence of the AIDS pandemic globally. In South Africa most children who are AIDS orphans live in township communities. They are often uncared for and unsupported by the community, and experience recurrent psychological trauma and much personal suffering. This results in health and social care professionals working with these children experiencing professional anguish. Whilst it is known that children who live as AIDS orphans in township communities suffer, there are no empirical studies reflecting the experiences of health and social care professionals providing care and support to these vulnerable children.
Objective: To explore and describe the experiences of primary health care nurses, social workers and psychologists caring for and supporting children who are AIDS orphans living in township communities in South Africa.
Design: The descriptive phenomenology research design incorporated an exploratory, contextual and descriptive approach. In-depth individual interviews were used to collect data from participants.
Setting: Participants were selected using purposive (nurses and social workers) and snowball sampling (psychologists) from four primary health care clinics and twelve satellite health care clinics, all located in township communities in Nelson Mandela Bay, South Africa. The participants were all caring for and supporting children who are AIDS orphans living in these communities.
Participants: The primary health care nurses (n = 10) and social workers (n = 8) were selected using criterion-based purposive sampling, whilst snowball sampling was used to select psychologists (n = 6). Participants are referred to as health and social care professionals.
Methods: In-depth individual interviews were recorded and transcribed. Independent coders reviewed the data and individually developed themes and subthemes, using thematic analysis.
Results: Although it is accepted that health and social care professionals experience anguish whilst providing care and support to AIDS orphan children, this study provides detail of this professional anguish, as presented in the following four main themes: 1) challenges in providing care and support; 2) unique experiences; 3) short-falls related to "best practice" in the health and social care system; and 4) development of holistic care.
Conclusions: The data provided deep and descriptive insights related to the anguish of health and social care professionals in caring and supporting the AIDS orphan children.

1. Introduction

AIDS (Acquired Immune Deficiency Syndrome) has devastated the social and economic fabric of African societies and made orphans of a whole generation of children who have, as a result, become the epicentre of the HIV/AIDS pandemic (Fassin, 2007). The total number of persons living with HIV in South Africa increased from an estimated 4.72 million in 2002 to 7.03 million by 2017 (Stats SA, 2017). South Africa is severely affected by the HIV/AIDS pandemic, with the largest number of HIV infections in the world (UNAIDS, 2017).

In 2017, an estimated 12.6% of the total population of South Africa (56.5 million) was HIV positive (Stats SA, 2017). Although recent statistics are lacking, there is significant variation in HIV prevalence across the nine provinces in South Africa. The Eastern Cape Province, where

---

[*] Corresponding author.
E-mail addresses: Sharron.frood@kcl.ac.uk (S. Frood), Dalena.vanrooyen@mandela.ac.za (D.R. van Rooyen), Esmeralda.ricks@mandela.ac.za (E. Ricks).

https://doi.org/10.1016/j.ijans.2018.07.002
Received 28 March 2018; Received in revised form 19 June 2018; Accepted 13 July 2018

Nelson Mandela Bay is situated, reportedly had an average prevalence rate among pregnant women of 30.4% in 2013 (South African National AIDS Council, 2016). Further, it is estimated that this pandemic affects approximately 280, 000 South African children from the age of 0–14 years (Hayman & Kidman, 2009; UNAIDS, 2017). If left untreated, morbidity and mortality as a result from Tuberculosis, pneumonia, and severe bacterial infections is high, especially in Sub-Saharan Africa where essential resources for adequate testing, and paediatric ARVs and child-friendly prevention programmes are often lacking (Avert, 2018; Frigati, Archary, Rabie, Penazzato, & Ford, 2018; Njuguna et al., 2018).

Children are especially vulnerable in the AIDS epidemic as, according to UNICEF (2016), about 13.4 million children and adolescents (0–17 years) worldwide had lost one or both parents to AIDS in 2015. In South Africa, there are an estimated 3.7 million orphans, about half of whom have lost one or both parents to AIDS (UNICEF, 2016). Children who are AIDS orphans living in South Africa, as in other African countries, suffer from recurrent psychological trauma which starts with the illness and death of their parents (van Dijk, 2008). The loss of a parent or caregiver due to AIDS often results in losing access to social grants, education and healthcare and carries an increased risk to the child of being exploited (UNICEF, 2015).

The majority of orphaned children living in Africa are from impoverished households (UNAIDS, 2009). In South Africa, these children often live in formal housing termed ‘townships’, or informal settlements (made up of tightly clustered informal shacks, often built as an extension of a township). In this study, townships is referred to both formal and informal housing structures. People living in these areas have limited access to water and lack sanitation, with only 46.7% of the South African population having piped water in their dwellings and 60% with a flush or chemical toilet. Unemployment in these areas is high (up to 60%) with household consumption expenditure of less than R16, 406.28 (approximately $1316.72) per annum. Correspondingly 25.7% of all households have indicated that their standard food consumption was less than adequate (Mahajan, 2014; Stats SA, 2012).

Given the prevailing conditions, orphans in these township communities are particularly vulnerable. They often experience a range of privations, including inadequate access to health care services and social security, insufficient food, restricted access to water, poor housing and limited educational opportunities. Conditions result in these children becoming ill, or living on the streets, where they are exposed to forced labour, organised crime, substance use and sexual and physical abuse (Molepo, 2015:1; Wagstaff & Therivel, 2017).

If the orphans living in the townships are not appropriately cared for, there will be a significant cost incurred in caring for and supporting them in the longer term. Such costs will include increased numbers of children living on the streets or in child-headed households, increased levels of juvenile delinquency and reduced literacy. As a consequence, an increased economic burden will be placed upon the state (van Dijk, 2008; UNICEF, 2015; Wagstaff & Therivel, 2017).

In South Africa, children living in township communities as AIDS orphans experience, in the first instance, care and support through primary health care nurses who are employed by the Department of Health, as well as social workers and psychologists who are employed by the Department of Social Development. These professionals, referred to as health and social care professionals in this study, are based in clinics and satellite clinics in the communities and provide care and support to the vulnerable children. They are employed to make visible to these children the government mandates of care and support, as constituted in the Bill of Rights in the Constitution of The Republic South Africa, in which it is stated that “that every child in South Africa has the right to basic nutrition, shelter, basic health care and social services” (section 29(1) (c) (Republic of South Africa, 1996).

Health and social care professionals’ care and support should be empowering, facilitating and enabling to help the children adapt to the new life reality of living as AIDS orphans in the township communities. To do this, it is essential that health and social care professionals sensitively care for and support the children’s unique needs in an informed, professional and well-resourced manner (HM Government, 2015). However, the costs to properly care and support these children are often high, leaving the professionals to experience anguish in turn as they are not able to provide the care and support needed by the children. This can lead to emotional turmoil and exhaustion, as well as burnout (Kuo, Cluver, Casale, & Lane, 2014; Mohangi & Pretorius, 2017; Molepo, 2015; UNICEF, 2015).

A systematic review on the prevalence and factors associated with burnout among frontline primary health care providers in low- and middle-income countries found that nurses providing HIV care in healthcare facilities in South Africa, as well as AIDS Volunteer Caregivers providing care and support to AIDS orphans, had the highest prevalence globally of emotional exhaustion and depersonalization associated with excessive time pressure and lack of support (Dugani et al., 2018). However, there is a paucity of literature that reflects self-reported experiences of health and social care professionals providing care and support to vulnerable AIDS orphan children. This study therefore explores and describes the experiences of primary health care nurses, social workers and psychologists in caring for and supporting children who are AIDS orphans living in township communities.

2. Methods

Qualitative research, based on a descriptive phenomenological design, was conducted using an exploratory, descriptive and contextual approach. Descriptive phenomenology focusses on a description of phenomena as humans experience them and include four steps: bracketing, intuiting, analysing and describing (Polit & Beck, 2012). Bracketing was used by keeping a field journal to describe and interpret the first author’s behaviour and responses in order to become aware of biases of preconceived assumptions. Intuition was used as the researchers remained open to the meaning attributed to their experiences. This study used thematic analysis to explore and describe the subjective experiences of caring for and supporting children who are AIDS orphans living in township communities in South Africa through the stories and worldview of primary health care nurses, social workers and psychologists. The study was conducted as part of a larger PhD study to develop strategies to provide care and support to AIDS orphans living in township communities. The individual interviews were conducted by the first author, a female fulltime PhD student in Nursing Science, under supervision of the second and third authors, who are both two PhD holders in Nursing Science and are academics who are experienced in conducting qualitative interviews.

The setting for this research was four primary health care clinics and twelve satellite clinics. As the geographical area these clinics served was large, satellite clinics were used which refer to sub-clinics at which primary health care nurses, social workers and psychologists go on a weekly or monthly basis to provide care and support to children who are AIDS orphans living in the communities. Both clinics and satellite clinics were situated in townships in Nelson Mandela Bay, which is a metropolitan area situated in the Eastern Cape, South Africa. Criterion-based purposive sampling for nurses and social workers was used to select participants from clinics and satellite clinics that have experience in providing care and support for a minimum of six months to AIDS orphans living in township communities. Snowball sampling was used to select psychologists working at satellite clinics that have had experience in providing care and support for a minimum of six months to AIDS orphans living in township communities. This type of sampling was used as it allowed to recruit psychologists as this population is small as compared to nurses and social workers and therefore a hard-to-reach target group. The gatekeepers, who were in charge of the clinics, were provided with information about the purpose and details of the study and requested approval to conduct the study at their healthcare facilities.

Following approval, the participants were personally approached and informed consent was obtained by issuing each participant with a letter which explained a summary of the researcher's background and interests for conducting the study, the purpose and objectives of the research study. No participant refused to participate. Each participant was given time to read the letter, before being given the consent form to sign. Two pilot interviews were conducted, each with a primary healthcare nurse and a social worker. No changes needed to be made to the interview schedule and the interviews were included in the main study.

The individual interviews were conducted in 2013 in English as the participants were all proficient in this language. The researcher had no established relationship with the participants prior to data collection which reduces bias. A date and time was arranged with each of the participants per clinic to minimise disruption of the workday. The participants were asked one question:

> How do you experience providing care and support to children who are AIDS orphans living in township communities?

Prompting and probing were used to encourage the participants to explore in greater depth and to reveal more detail and description of their experiences as well as recommendations that could be made to improve the quality of care and support provided to children who are AIDS orphans living in the townships. Data collection was continued until data saturation was achieved and no follow-up interviews needed to be carried out. Field notes were written up after each interview. Interviews were audio-recorded and took approximately 45 minutes to an hour and were audio recorded and transcribed verbatim. Transcripts were returned to the participants for comments and/or corrections, and then subject to thematic analysis. Tesch's model for the thematic analysis was used, which entailed steps such as carefully reading the transcript, creating a list of topics and then grouping similar topics together into key topics or themes and, if necessary, re-coding existing data (Creswell, 2014). All interviews were double coded by the researchers and the independent coder to ensure reliability of the coding. The data were organised according to emergent key themes and subthemes, which were then agreed upon by all authors. In the analysis, the focus was upon the health and social care professionals self-reported everyday experiences in their respective roles in caring for and supporting children who are living as AIDS orphans in township communities.

2.1. Trustworthiness

The interview question was developed and reviewed by an expert in qualitative data analysis to ensure it generated data required to answer the research aim. A thick description of the context and findings was provided to support transferability. Data analysis was conducted by an independent coder, and consensus was reached regarding the themes by the authors. A dense description of the research results was given, supported with quotations of the participants to ensure transferability. In presenting the data, the researchers remained as close to the evidence as possible (Creswell, 2014).

2.2. Ethical considerations

Permission to conduct this study was obtained from the Faculty Post Graduate Studies Committee (FPGSC) at Nelson Mandela University and the Directorate of Epidemiological Research and Surveillance Management at the Eastern Cape Department of Health, in order to conduct research in the primary health care clinics in Nelson Mandela Bay municipal area. The ethics approval number is H12-HEA-NUR-001. Further permission was obtained from the management of the District Health Services. Additionally, permission was gained from the director of the Department of Social Development and the managers of the satellite clinics. Written consent was obtained from the above entities before the research study commenced. The following principles were upheld throughout this study: respect for human dignity and justice by using informed consent, anonymity through coding and recoding of the data rather than linking data to particular participants, and confidentiality in handling and storing the data on a pass-word protected computer.

3. Results

In total 24 individual interviews were conducted with 10 primary healthcare nurses (participants 4–7, 9–11, 13, 15 and 22), 6 psychologists (participants 8, 12, 14, 17, 23–24) and 8 social workers (participants 1–3, 16, 18–21). All participants were female except for one participant. All participants were English speaking and had more than six months experience of working with children who are AIDS orphans living in township communities.

The data collected provided valuable insights regarding the self-reported experiences of professionals caring for and supporting children who are living as AIDS orphans in township communities in South Africa. The results are presented under the four major themes identified through the thematic analysis.

4. Theme 1: challenges in providing care and support

When children who are living in township communities become AIDS orphans, every paradigm of their life alters. Furthermore, they experience physical, psychological, social and financial distress, which is exacerbated by insufficient professional and material resources to provide them with the necessary care and support.

Health and social care professional study participants, who witnessed the suffering of AIDS orphans daily, reported finding their needs overwhelming as they listened to their stories of pain and devastating neglect. Many health and social care professionals used the words 'destitute', 'discarded', 'abandoned' and 'bottom of the pile' when they described these children.

Study participants reported feeling that daily exposure to the lives of these children, which was full of suffering and hardship, caused them professional anguish as it was beyond the experience of their own lives. The lives of the AIDS orphans was experienced as being overwhelmingly challenging and deeply sorrowful, as reflected in the following quotations:

> *These children are the bottom of the pile; there is a total lack of support services for orphans and vulnerable children. They are hungry, malnourished, and sick and grief-stricken. We see this every day.* [Participant 10, pg. 4].
> *As a psychologist, I hear the same story over and over again: stories of suffering and pain; pain of loss, pain of poverty. Somehow it seems to make a difference in the lives of children to just acknowledge they are hungry. I can't take their hunger away but somehow by acknowledging the children's suffering it seems to help, but I feel overwhelmed by this because, I can't feed all the hungry people I see.* [Participant 12, pg. 3].
> *The other day I spent the whole day filling in Foster Care placement forms with a family. It's so demoralising because I know it will take so long for the grant to come through. I hear the same story of suffering of children who are orphans every day…. It's so hard to listen to their pain. I go home exhausted because how can I not care? I felt overwhelmed by the number of children whom I see who are orphans and who I must place in foster care. It is never ending, and every day there are referrals. It's overwhelming.* [Participant 22, pg. 3].

Participants felt that the lack of health and social support services was not at all conducive to the provision of holistic care and support to the children. These professionals saw suffering every day and reported feeling anguish, pain, sorrow and dismay as they were unable to adequately care and support the children. Participants repeatedly spoke about inadequate health care, financial support, psycho-social care and referral systems, which were buckling under the strain of the sheer numbers of children trying to access the clinics and satellite clinics for care and support. Participants used words such as 'disgraceful', 'shameful', 'inadequate' and 'appalling' when recounting how children who were AIDS orphans living in the townships experienced care and support. Their responses are highlighted in the following quotations:

> *Children who come to this clinic for their ART, TB or any other medication for illnesses, need more support than we can give when they are orphans. They need psycho-social support. We can't cure their hunger, nor can we help them with their grant applications. They need social workers to visit them at their homes. We have totally inefficient referral systems in South Africa.* [Participant 24, pg. 4].
> *This child came to me one day: 'There is no money at home to buy food'. I filled out a form, referring this family to receive a food parcel. Six months and still nothing, six months!!! So, I gave him money from my purse.* [Participant 18, pg. 5].

5. Theme 2: unique experiences

Some experiences were unique to the individual group of participants as primary health care nurses, social workers and psychologists each expressed their unique experiences. For example, primary health care professionals told the researcher that a critical lack of primary health care professionals and associated health and social care professionals was obstructive in the provision of care and support to the vulnerable AIDS orphan children and that this state of affairs increased the disappointment and professional anguish of the professionals. The study participants reported that they experienced feeling sad and angry. They saw how HIV/AIDS caused suffering in the lives of people living in the township communities and were overwhelmed by working in failing systems which lacked adequate resourcing, as outlined in the following quotations:

> *Sometimes the children who come to see me—they just need time to talk and be understood. They don't just want tablets; they want time and relationship. We are so few nurses; I can't give them the time they need. I often feel guilty about this.* [Participant 7, pg. 3].
> *Many of the AIDS orphans who come to this clinic are living in child-headed-households. They have huge needs that are beyond the scope of this clinic because we are too few staff and we have too few resources. They suffer and we see their suffering. It's very horrid.* [Participant 10, pg. 2].
> *I got to a point where I couldn't feel anymore. I couldn't face seeing any more distress. I was sad all the time and lost my ability to care. I realised that day I was burnt out because of all of the distress I experienced. I was off work for three months because of this. I still ache now but in a different way. I was scared because of how distressed I felt.* [Participant 15, pg. 5].

Social workers spoke of the appalling and desperate conditions in which they found children who were living as AIDS orphans in the township communities. Social workers found barriers in all social systems set up to support the children. Food parcels took six months to arrive, child support grants (CSG) took months to process, and foster care grant (FCG) applications took, on average, two years to be awarded to foster carers. Social workers spoke of a fragmented and cumbersome social system which was inadequate to meet the care and support needs of the children.

Social workers were weary because of the lack of resources and poor working conditions they were exposed to daily. They attributed their high caseloads to being obstructive in providing much needed support to the children. They further expressed the distress and discouragement they experienced as they could not provide immediate help for these children and their families. They felt helpless as they were unable to intervene in desperate situations and to alleviate the suffering of the children. Yet they were motivated to do what they could through providing for the children through their own purses and the charity of their friends, relatives and colleagues.

> *Yesterday I went to the home of four children who are AIDS orphans living in a child-headed household. The house had no windows, no mattress on the bed, just rusty metal springs and no food. These children were grief stricken, sad, cold and hungry. I can offer them advice and write referrals but this is not enough. I was so sad that I could not help and support them as they needed. So, I gave them money for bread from my own pocket.* [Participant 12, pg. 7].

The psychologists indicated that the extent of the suffering they heard and saw from the AIDS orphans caused them to feel overwhelmed. They saw neglect, heard neglect and the unending story of loss and pain.

> *It's so difficult to listen to the heart rendering stories of these AIDS Orphans. It's difficult for them to talk, but when they do it's like a waterfall. They experience multiple losses: they lose their parents, their standing in the community, their education, their friends and their dignity because of poverty. They are angry; very, very, angry. Because of this anger they have difficult behaviour and often leave school to consume alcohol and drugs because the emotional pain is too hard for them to bear.* [Participant 8, pg. 3].
> *There are many practical difficulties children living in the township communities face. These children live with a deep sense of sadness. If these children are also HIV-positive, they also face a lot of fear because of the vulnerabilities of their own health.* [Participant 8, pg. 1].
> *Children with repressed grief find it difficult to concentrate in school. They may not even be able to function in the school environment, because the school environment reminds them when they did have parents and what their life was like then. They can become difficult—acting out, being aggressive and disengaging in relationships that used to be important to them.* [Participant 8, pg.2].

Psychologists found situational constraints and the complex emotional needs of AIDS orphans as hindrances to establishing a therapeutic trusting relationship with them. This led psychologists to experience feelings of being helpless, ill equipped and ill resourced to help the children.

> *I see so much repressed anger in children who are AIDS orphans because they have suffered. I am sure this is why we see such violence in our townships because of all the suffering people endure and they can't express their anger in a healthy way so they repress it.* [Participant 7, pg. 6].
> *You can see people waiting outside my door. It takes time to counsel children because of all they are processing as AIDS orphans and trust is initially fragile and must be built upon with every interaction I have with them. These children have been hurt, abandoned and let down. They won't trust me if I am distracted because of being pre-occupied by my work-load.* [Participant 14, pg. 7].

It is clear from the above extracts from participant interviews that engaging with the emotional turmoil and levels of suffering of the AIDS orphans, on a continuous basis, and the inability to appropriately care and support for these children, causes the health and social care professionals in this study to feel distress. For example, psychologists in this study experienced listening to the laments of children living as AIDS orphans as unbearable, caused stress, anxiety and depression. As one participant explained: "It's unbearable at times to listen and to see the psychological and emotional distress children experience when they become AIDS Orphans" [Participant 12, pg. 1]. The psychologist's experiences of distress were intensified due to feeling constrained by lack of resources when attempting to assist children process their grief at becoming AIDS orphans and to develop resilience. This caused some individuals to withdraw emotionally, as explained by one respondent who explained: "My own soul is saturated with suffering and pain" [Participant 12, pg. 1].

6. Theme 3: short-falls related to best practice in the health and social care system

Participants of this study experienced shortfalls relating to best practice in terms of upholding the principle of best interests for the child within the health and social systems in which they worked. These shortfalls meant that children who were AIDS orphans and on ART for HIV infection, and their caregivers, received inadequate education regarding their ART treatment and, thereby, caused further suffering to vulnerable children and their families.

> *We know what we want to do and should do; but we can't because of the systems in which we work. AIDS orphans and their families suffer because of this. How can we give ART to children who are hungry and have no food at home?* [Participant 12, pg. 7].
> *Some children don't even know they are HIV-positive because they have had it since birth. They stop taking this medication because they don't know why they are taking it. Their grandparents then come to me for advice. These children stop taking this medication because they don't know they are HIV positive. Some think they are taking ART for asthma.* [Participant 12 pg. 12].

Participants reported that they experienced a lack of assistance from other professionals concerning helping the children in their grief, emphasising how it was indeed 'best practice' concerning the 'best interests' of these children to help them to process the grief of losing their parent/parents. Participants understood that the grief of AIDS orphans was complex but, owing to the health and social care system shortfalls, they were unable to give the assistance required. This was outlined in the following quote:

> *Children who are AIDS orphans withdraw socially because they feel grief. It's our responsibility as professionals to help them talk, but we don't have time. They need to talk to develop coping strategies but no-one has time to listen because there are too many of them.* [Participant, 16, pg. 3].

7. Theme 4: need for the development of holistic care and support strategies

Participants spoke about the need for the development of holistic care and support strategies so that the practice gap could be filled by the necessary health and social care professionals, and associated resources, to provide care and support to this vulnerable, neglected and anguished group of children. Being innovative in the process of improvement, and the motivation to do what was right, good and fair for these children, were the participants motivation for continuing in their respective professional roles to assist in caring for and supporting the children. One participants described their commitment as driven by: "giving hope to the hopeless, and doing good" [Participant, 6, pg. 6]. Others reported as follows:

> *I can say children who are AIDS orphans receive the worst care and support of anyone we see in this clinic. They are left to fend for themselves and live very poor lives, full of suffering and pain. It's not right that we see them and send them away to homes with nothing in.* [Participant 5, pg.3].
> *I can say when children become AIDS orphans living in the townships they become very poor. There are few people and resources to help them and their families and this needs to be improved very quickly.* [Participant 12, pg. 6].
> *We don't have a plan for these children who are AIDS orphans. How we help them most is by writing referrals and by giving from our own pockets. If we have a well-resourced plan I can say these children who are AIDS orphans will be helped, but currently they suffer and we see this suffering.* [Participant 19, pg. 8].

Participants felt very strongly that a multidisciplinary team collaboration response was required to help these children. They used words like 'togetherness', 'partnership' and 'contribution' in their discussion of what should happen.

> *You know, if we could refer to other professionals, and these referrals worked, then children who are AIDS orphans would get the help they needed through the multi-disciplinary team working together. These children suffer because they wait as our systems simply don't work.* [Participant 22, pg. 1].
> *What would be really good is if we had the multidisciplinary team under one roof. This would help these children a lot. They would only have to walk down the corridor and not travel across town. We expect families already in need to travel and they can't as they have no money. They suffer even more because of this.* [Participant 22, pg. 7].

Health and social care professionals in this study experience anguish whilst providing care and support to AIDS orphan children, due to challenges in providing care and support as well as short-falls related to "best practice" in the health and social care system, resulting in the participants giving recommendations to the development of holistic care for these children.

8. Discussion

There is scarcity of literature related to the self-reported experiences of health and social care professionals caring for and supporting children who are AIDS orphans living in township communities in South Africa. What is known is that when children become AIDS orphans and are living in these communities they suffer. The professionals caring for and supporting these children see and hear this suffering in their daily working lives.

Health and social care professionals who engage with people who are anguished every day often experience sadness, depression, fatigue, loss of sleep, loss of appetite and anxiety (Molepo, 2015). Participants used such words as 'sorrow', 'disappointment', 'loss', 'hardship', 'pitiful', 'grief',' turmoil', 'despair', 'helplessness', 'overwhelmed', 'hopeless' and 'suffering' to describe their experiences in caring for and supporting AIDS orphan children. Moreover, providing care for HIV-positive children is extremely stressful for health and social care professionals (Molepo, 2015).

Working under such conditions may provoke feelings of helplessness among health and social care professionals, and lead to emotional withdrawal as a mechanism for blunting the tension of caring for suffering, sick and dying children. Whilst this helps professionals to cope with feelings of distress, it may compromise the child's care (Govender et al., 2006). Professionals caring for patients in the HIV/AIDS pandemic are more likely to suffer burnout due to the higher levels of stress when compared to other professionals working in fields such as oncology (van Dijk, 2008).

It is clear from the data that the health and social care professionals who participated in this study felt that their contribution made a difference to the lives of the AIDS orphan children. Through, at times, buying bread with their own money, offering kind words of hope, listening and, on occasion, assisting with school homework, they helped the children in ways they considered to be 'just'. Social workers were committed to being persistent in CSG and FCG applications, because they considered this the "right thing to do".

Participants conveyed their commitment to "being moved by compassion to help and motivated to make a difference", "speaking kind words full of hope" to the children and doing acts of kindness to "help them, through buying bread, school uniforms and shoes from their own pockets". These professionals felt that their contribution made a difference in the lives of these children, whose needs were great, but in doing so they described themselves as experiencing anguish.

However, study participants spoke about 'best practice shortfalls' increasing the suffering of the AIDS orphan children. If the 'best practice' intention regarding management of the health and social care systems is to uphold the principle of 'best interests for the child', whatever is done in South Africa must be "nationally enabling and locally empowering" (Doherty & Gilson, 2011:i).

In South Africa, there is a legislative framework that the professionals are expected to uphold whilst caring for AIDS orphans. For example, the Children's Act of 2005 (Republic of South Africa, 2005), which has its roots in the Constitution of South Africa, stipulates the rights of children. The Convention of the Rights of the Child, of which the South African Government is signatory, "upholds the concept of 'best interests' of a child as of paramount importance in every matter concerning the child; (d) to make provision for structures, services and means for promoting and monitoring the physical, psychological, intellectual, emotional and social development of children" (UNAIDS, 2011:3).

All participants of this study mentioned the Children's Act and the necessity of upholding the provisions of the Act. Yet the majority of these professionals acknowledged that they fell short in their professional responses to these children, and experienced challenges operationalizing government policy rooted in these legislative frameworks, due, as indicated by one participant, to inadequate numbers of health and social care professionals available. It was reported that there were "too few of us to help all the children who come to our clinic every day. It's like that all over South Africa" [Participant 4, pg. 5].

As of October 2012, the South African Council for Social Service Professionals reported that there were 17, 583 registered social workers—a 60% shortage of social workers in terms of the requirements of the Children's Act alone (Republic of South Africa, 2005). In 2010, the vacancy rate regarding the number of posts for nurses in the public sector was 46.3%. In the Eastern Cape Province, it was 59% (George et al, 2010). Thus, close to half of all of the registered nursing posts are vacant in the public health sector. Although more recent statistics are not available, this problem has been said to have worsened (MoneyMarketing, 2016)

With regard to mental health care professionals, there were 207 psychiatrists and 364 psychologists employed in South Africa in 2014—one psychiatrist per 256 410 people and one psychologist per 144 928 people (Flanagan, 2014). With a population of 56.5 million (in mid-2017) of which 3.7 million are orphans (Stats SA, 2017), these figures clearly demonstrate the insufficient numbers of health and social care professionals available to care for and support vulnerable children in the HIV/AIDS pandemic and living in cycles of extreme poverty and loss.

Another challenge that was experienced by the professionals in this study was the lack of resources and poor working conditions they were exposed to daily. Research carried out by the Children's Institute at the University of Cape Town in 2011 into the funding of services required by the Children's Act indicated the difficulty of funding the provisions. The full cost of the national Implementation Plan of the Children's Act, defined as "good practices and norms for all services" would cost R59.2 billion (approximately $475.9 million) (Budlender et al,. 2011). The R3.4 billion (approximately $27.3 million) allocated by the provincial department of the Eastern Cape Province in 2010/2011 is only 5% of the full cost of the national Implementation Plan.

The National Plan of Action for Children seeks to give meaning and visibility to rights enshrined within the South African Constitution, with an overarching objective to invite "all of society to work together to implement proposals to create a society which is just and fair" (Hall, Woolard, Lake, & Smith, 2012). South African legislation pertaining to the rights of children is well written and comprehensive. Yet, without implementation it remains non-visible in the lives of vulnerable children such as AIDS orphans living in townships.

What is apparent is that, in order to realize care and support for children living as AIDS orphans in the township communities, there needs to be a review of the current government health and social welfare responses related to capacitation, collaboration and configuration of health and social care systems which exist to meet the care and support needs of these vulnerable children. More comprehensive care and support for these children would also lessen the suffering experienced by the health and social professionals as they will feel they are able to assist the children more effectively. Until such systems are in place, the health and social welfare professionals can be assisted in various ways. For example, counseling should be offered in order for them to voice and deal with their professional anguish. To alleviate their workload, assistance could be offered from the health care workers from the community. The professionals are also encouraged to advocate for their needs through available platforms, such as professional Councils and Boards. Finally, as there is little literature about the experiences of health and social care professionals caring and supporting AIDS orphans in township communities, qualitative research to explore this topic further and the needs of these professionals would therefore be recommended.

9. Conclusion

The data produced in this research study provided detail regarding the experiences of health and social care professionals caring for and supporting children who are AIDS orphans living in township communities. Challenges in operationalising the care and support response initiatives, as mandated for in health and social care legislations in South Africa, resulted in different forms of anguish and challenges in the care and support for AIDS orphans as experienced by the professionals interviewed.

Although health and social care interventions for such vulnerable children are comprehensively provided for in government legislation and regional government policy, the mobilisation of the required responses remains inadequate, resulting in participants indicating the need for the development of holistic care and support strategies. Until such interventions are in place at the necessary level, health and social care professionals should be assisted in caring for and supporting AIDS orphan children through counselling, assistance in their workload and advocacy to address their needs. This study was limited to health and social care professionals in the Nelson Mandela Bay, which is an urban area. As little research has been done on the topic, more qualitative studies should be done exploring this topic further. The results of this study can be used to inform holistic responses in providing care and support to health professionals, so that AIDS orphans' real needs can be better met through well-resourced and informed professional care and support responses.

Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at https://doi.org/10.1016/j.ijans.2018.07.002.

References

Avert. 2018. Children, HIV and AIDS. Available at: https://www.avert.org/professionals/hiv-social-issues/key-affected-populations/children (Accessed 22 May 2018).

Budlender, D., Williams, L., Saal, Q., Sineke, T., & Proudlock, P. (2011). *Funding of Children's Act-related services. Commissioned by the United States Agency for International Development, the United Nations Children's Fund South Africa, and the South African National Treasury. Prepared by the Community Agency for Social Enquiry and the Children's Institute, University of Cape Town.* Cape Town: University of Cape Town.

Creswell, J. W. (2014). *Research design. Qualitative, quantitative, & mixed methods approaches* (4th ed). Los Angeles: SAGE.

Doherty, J., & Gilson, L. (2011). *Lessons for innovative health management in the public sector. Report of Conference Celebrating Innovative Health Management In the Public Sector, 20–30 June 2011. Cape Town. Oliver Tambo Fellowship Programme.* University of Cape Town [Pdf]. Available at: http://uct-heu.s3.amazonaws.com/wp-content/uploads/2011/11/Health-Management-report_final.pdf (Accessed 5 March 2018).

Dugani, S., Afari, H., Hirschhorn, L. R., Veillard, J., Martin, G., Lagomarsino, G., Basu, L., & Bitton, A. (2018). Prevalence and factors associated with burnout among frontline primary health care providers in low- and middle-income countries: A systematic review [version 1; referees: awaiting peer review]. *Gates Open Research, 2: 4.* https://doi.org/10.12688/gatesopenres.12779.1.

Fassin, D. (2007). *When bodies remember.* London: University of California.

Flanagan, L. 2014. SA short of psychologists. IOL News. 13 November. [Online]. Available at: http://www.iol.co.za/news/politics/sa-short-of-psychologists-1779737 (Accessed 6 March 2018).

Frigati, L., Archary, M., Rabie, H., Penazzato, M., & Ford, N. (2018). Priorities for decreasing morbidity and mortality in children with advanced HIV disease. *Clinical Infectious Diseases, 66*(2), S147–S151 (doi.org/10.1093/cid/ciy013).

George, G., Atujuna, M., Gentile, J., Quinlan, T., Schmidt, E., Tobi, P., & Renton, A. (2010). The impact of ART scale-up on health workers. Evidence from two South African districts. *AIDS Care, 22*(01), 77–84 https://doi.org/10.1080/09540120903544439.

Govender, L., Rochat, T., Richter, L., & Rollins, N. (2006). Paediatric Nursing in the context of the HIV/AIDS epidemic in resource-poor settings. *Holistic Nursing Practice, 20*(5), 247–254.

Hall, K., Woolard, I., Lake, L., & Smith, C. (2012). *South African child gauge.* Cape Town: Children's Institute, University of Cape Town [Pdf] Available at: http://www.ci.uct.ac.za/sites/default/files/image_tool/images/367/Child_Gauge/South_African_Child_Gauge_2012/sa_child_gauge2012.pdf (Accessed 6 March 2018).

Hayman, J., & Kidman, R. (2009). Declining family resources and the community safety net. *AIDS Care, 21*(S1), 34–42 (10.1080/09540120902927593).

HM Government, UK. 2015. Working together to safeguard children. A guide to inter-agency working to safeguard and promote the welfare of children. [Pdf] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/592101/Working_Together_to_Safeguard_Children_20170213.pdf (Accessed 5 March 2018).

Kuo, C., Cluver, L., Casale, M., & Lane, T. (2014). Cumulative effects of HIV illness and caring for children orphaned by AIDS on anxiety symptoms among adults caring for children in HIV-endemic South Africa. *AIDS Patient Care STDS, 28*(6), 318–326 (10.1089/apc.2013.0225).

MoneyMarketing, 2016. The real cost of the skills shortage in the SA health sector. May 18. [Online] Available at: https://www.moneymarketing.co.za/the-real-cost-of-the-skills-shortage-in-the-sa-health-sector/ (Accessed 26 February 2018).

Mahajan, S. (2014). *Economics of South African townships: Special focus on Diepsloot.* Washington, DC: World Bank Group [Pdf] http://documents.worldbank.org/curated/en/217211468302413395/pdf/899170PUB0978100Box385216B00PUBLIC0.pdf. (Accessed 2 February 2018).

Mohangi, K., & Pretorius, C. (2017). On the periphery of HIV and AIDS: Reflections on stress as experienced by caregivers in a child residential care facility in South Africa. *SAHARA J, 14*(1), 153–161 (10.1080/17290376.2017.1389300).

Molepo, L. (2015). Professional challenges experienced by child youth care workers in South Africa. *Children and Youth Services Review, 56*(2015), 149–160.

Njuguna, I. N., Cranmer, L. M., Otieno, V. O., Mugo, C., Okinyi, H. M., Benki-Nugent, S., Richardson, B., Stern, J., Maleche-Obimbo, E., Wamalwa, D. C., & John-Stewart, G. C. (2018). Urgent versus post-stabilisation antiretroviral treatment in hospitalised HIV-infected children in Kenya (PUSH): a randomised controlled trial. *Lancet HIV, 5*, e12–e22.

Polit, D. F., & Beck, C. T. (2012). *Nursing research: Generating and assessing evidence for nursing practice* (Ninth Edition). Philadelphia: Lippincott Williams & Wilkins.

Republic of South Africa (1996). *Constitution of the Republic of South Africa. Act 108 of 1996.* Pretoria: Government Printers.

Republic of South Africa (2005). *Children's Act 38 of 2005.* Pretoria: Government Printers.

Stats SA (Statistics South Africa) (2012). *The South Africa I know, the home I understand.* Pretoria: Stats SA [Pdf] http://www.statssa.gov.za/Census2011/Products/Census_2011_Pictorial.pdf. (Accessed 2 February 2018).

Stats SA (2017). *Mid-year population estimates.* Pretoria: Stats SA [Pdf] http://www.statssa.gov.za/publications/P0302/P03022017.pdf (Accessed 26 February 2018).

South African National AIDS Council. 2016. Annual Progress Report 2014/2015. [Pdf] http://sanac.org.za/wp-content/uploads/2016/04/EASTERN-CAPE-ANNUAL-PROGRESS-REPORT_Final.pdf. (Accessed 3 February 2018).

UNAIDS. 2009. Global health publications. [Pdf] http://data.unaids.org/pub/report/2009/globalhealthpublications_en.pdf (Accessed 2 February 2018).

UNAIDS. 2011. World AIDS Day Report. [Pdf] http://www.unaids.org/sites/default/files/media_asset/JC2216_WorldAIDSday_report_2011_en_1.pdf (Accessed 26 February 2018).

UNAIDS. 2017. Ending AIDS: Progress towards the 90–90–90 targets. [Pdf] http://www.unaids.org/sites/default/files/media_asset/Global_AIDS_update_2017_en.pdf (Accessed 26 February 2018).

UNICEF. 2015. Biennial Report South Africa 2014–2015. [Pdf] https://www.unicef.org/southafrica/SAF_resources_biennialreport2014_2015.pdf (Accessed 26 February 2018).

UNICEF. 2016. Seventh Stocktaking Report on Children & AIDS. [Pdf] https://data.unicef.org/wp-content/uploads/2016/12/HIV-and-AIDS-2016-Seventh-Stocktaking-Report.pdf (Accessed 5 March 2018).

van Dijk, D. (2008). *Beyond their age.* Leiden: African Studies Centre.

Wagstaff, J. & Therivel, J. 2017. Orphans: Foster care and adoption; Global perspective. [Pdf] https://www.ebscohost.com/assets-sample content/SWRC_Foster_Care_and_Adption_Global_Perspective_QL.pdf (Accessed 5 March 2018).